United Nations CRPD/C/SR.397

Convention on the Rights of Persons with Disabilities

Distr.: General
31 August 2018

Original: English

Committee on the Rights of Persons with Disabilities
Twentieth session

Summary record (partial)* of the 397th meeting
Held at the Palais des Nations, Geneva, on Monday, 27 August 2018, at 3 p.m.

Chair: Ms. Degener

Contents

General comments

Discussion on the draft general comment on articles 4 (3) and 33 (3) of the Convention

* No summary record was prepared for the rest of the meeting.

This record is subject to correction. Corrections should be set forth in a memorandum and also incorporated in a copy of the record. They should be sent within one week of the date of the present record to the Documents Management Section (DMS-DCM@un.org).

Any corrected records of the public meetings of the Committee at this session will be reissued for technical reasons after the end of the session.

GE.18-14126 (E) 300818 310818

1814126

Please recycle

The meeting was called to order at 3 p.m.

General comments

Discussion on the draft general comment on articles 4 (3) and 33 (3) of the Convention

1. **Mr. Langvad** said that a working group, of which he was the chair, had been established to draft a general comment on articles 4 (3) and 33 (3) of the Convention, which dealt with the participation of persons with disabilities in the implementation and monitoring of the Convention. The working group had held consultations with, and called for written submissions from, organizations of persons with disabilities, specialized agencies, non-governmental organizations (NGOs), academia and human rights bodies. With the invaluable assistance of International Disability Alliance and the Civil Society Coordination Mechanism, the working group had organized a general discussion on articles 4 (3) and 33 (3) ahead of the eleventh Conference of States Parties to the Convention on the Rights of Persons with Disabilities. The aim of the discussion had been to determine the key issues to be addressed by the general comment on articles 4 (3) and 33 (3) and identify good practices at the national level.

2. Submissions from stakeholders had been analysed in detail and had proved to be crucial to the further development of the general comment. Issues relating to the definition of "representative organization" and the scope of the involvement of such organizations, including organizations of parents and relatives of persons with disabilities, had been clarified. Emphasis had been placed on the need to provide support and funding for such organizations and to include them in decision-making and monitoring processes, regardless of the cultural background, sexual orientation or political beliefs of their membership. Further work had been done to elaborate on the scope, criteria and legal effects of the involvement of persons with disabilities through their organizations. Two public meetings had been scheduled during the current session to enable the Committee to receive input on the draft general comment from as many stakeholders as possible.

3. **Ms. Pedreros** (Office of the United Nations High Commissioner for Human Rights) said that the working group had received 38 written submissions from a variety of stakeholders, including Governments of States parties to the Convention, the Global Alliance of National Human Rights Institutions, national human rights institutions, independent bodies monitoring the Convention, organizations of persons with disabilities, academics, civil society organizations, former Committee members and the Special Envoy of the Secretary-General on Disability and Accessibility.

4. **Ms. Rinaldi** (Secretary of the Committee), reading out a statement on behalf of Child Rights Connect, said that the draft general comment should recognize that children with disabilities were discriminated against on the basis of both age and disability and call for tailored policies designed to tackle obstacles to their empowerment. In order to reflect the standards set out in the Convention on the Rights of the Child relating to the rights to the freedom of association and of expression and the right to be heard, the general comment should include child-led organizations and initiatives in the definition of "representative organization". It should also recognize that children with disabilities required specific participation processes and elaborate on the measures to be taken to provide disability- and age-appropriate assistance to facilitate children's participation and to enable members of their families, teachers and disability workers to develop a rights-based perspective on child participation and to offer suitable support. The Committee should take part in the day of general discussion of the Committee on the Rights of the Child on protecting and empowering children as human rights defenders, scheduled to take place on 28 September 2018, and the 2019 full-day meeting of the Human Rights Council on the theme of empowering children with disabilities for the enjoyment of their human rights, including through inclusive education.

5. **Ms. Jenni** (insieme Schweiz) said that insieme Schweiz was an umbrella organization of associations of persons with disabilities and their families which advocated for the rights of persons with disabilities. She wished to underscore the importance of ensuring that voting information was accessible to persons with disabilities.

6. **Ms. Gysi** (insieme Aarau-Lenzburg), noting that members of her organization would be meeting with Swiss parliamentarians in the near future, said that persons with disabilities and their families needed support from their organizations to learn about political processes and about how to make their voices heard.

7. **Ms. Hofstetter** (insieme Aarau-Lenzburg) said that, through her participation in the "insieme inklusiv" project, she had learned valuable organizational skills and had been able to participate in decision-making.

8. **Ms. Swenson** (Inclusion International) said that at her organization's recent world congress members had adopted a call to action from self-advocates, demanding the inclusion of persons with intellectual disabilities in wider society, an end to discrimination, real jobs for real pay, inclusive education and the closure of institutional care facilities. Inclusion International recognized that families of persons with intellectual disabilities provided a pathway to inclusion and required support.

9. **Ms. Quan-Chang** (International Disability Alliance), speaking on behalf of People with Disability Australia and Disabled People's Organizations Australia, said that the draft general comment should take into account persons with disabilities who experienced multidimensional and intersectional discrimination, in particular those who were lesbian, gay, bisexual, transgender or had other sexual orientations or gender identities (LGBT+). Such persons faced high levels of social exclusion, isolation and violence, were denied the right to support and to form relationships and were often subjected to forced medical interventions and treatment.

10. The Committee had begun to address intersectional discrimination through its general comment No. 3 (2016), on women and girls with disabilities, and through numerous concluding observations and lists of issues. She urged it to continue to focus on discrimination against persons with disabilities who were members of the LGBT+ community. The failure to include any reference to such persons in the final versions of general comment No. 4 (2016), on the right to inclusive education, general comment No. 5 (2017), on living independently and being included in the community, and general comment No. 6 (2018), on equality and non-discrimination, had been disappointing. She was deeply concerned to see that references to the LGBT+ community had been placed in brackets in the draft general comment. The jurisprudence of the Committee must continue to encompass persons with disabilities who were lesbian, gay, bisexual, transgender or had other sexual orientations or gender identities.

11. **Mr. Kofmel** (Autistic Minority International) said that, although paragraphs 1 and 2 of the draft general comment indicated that a range of organizations of persons with disabilities had been involved in the process of drafting the Convention, no persons with autism had taken part in that process. Issues affecting persons with autism had not been addressed in the negotiations on the Convention, and consequently some aspects of the Convention went against their interests — for instance, the focus on early intervention in article 25 (b). For autistic children, such interventions often included applied behaviour analysis, a practice that caused extreme trauma and was viewed by many as being akin to torture. Thus, contrary to the claim made in the draft general comment, the negotiations concerning the Convention did not constitute an excellent example of best practice in implementing the principle of full and effective participation.

12. The definition of "organization of persons with disabilities" in the draft general comment was both restrictive and prescriptive, and effectively excluded most organizations of persons with autism. Indeed, much of the draft general comment was not applicable to the reality of persons with autism and would only serve to further exclude them. Autistic persons organized their activities informally, mainly through social media, which meant that they were not "representative organizations" as the term was defined in the general comment. Organizations of persons with autism were an example of self-advocacy organizations, which, as was recognized in the general comment, were often discriminated against and denied legal status. As such, they did not have, and could never achieve, the global reach required for membership of International Disability Alliance, which therefore did not represent persons with autism. The fact that the Alliance was a key supporter of the

Committee went a long way towards explaining why no autistic person had ever been invited to speak at one of the Committee's days of general discussion.

13. Autistic Minority International took the view that organizations of non-autistic parents of autistic children did not represent the interests of those children but rather the interests of families of autistic children. Such organizations would always undermine the interests of autistic persons, including those of their children, as those interests did not align with the priorities of families. It was important to make clear that the interests of autistic persons should be represented by autistic children and adults themselves and by their often informal, voluntary and self-funded groups, networks and organizations, rather than by organizations of their non-autistic parents. The Committee should be aware that organizations of non-autistic parents of autistic children often included a few token autistic persons among their staff. However, in order to secure a position in such an organization, an autistic person had to subscribe to its policies, which reflected the priorities of non-autistic parents rather than those of autistic persons themselves. The Committee should also be aware that autistic persons and other persons with disabilities who participated in the work of organizations of persons with disabilities risked losing their disability benefits, as their participation was wrongly taken as evidence of their ability to work.

14. The draft general comment did not take into account the fact that autistic persons were excluded from umbrella organizations of persons with disabilities, which preferred to work with parents of autistic children and autism charities. Moreover, it seemed to encourage the establishment of organizations of parents rather than self-advocacy organizations. That approach could undermine the involvement of autistic persons and consultation with such persons.

15. The specific accessibility requirements of autistic persons should be taken into account in the general comment. Even the Committee's general comment No. 2 (2014), on accessibility, had not addressed the specific requirements of autistic persons. Accessibility arrangements for other disability groups often made consultations and physical meetings less accessible to autistic persons, as they led to sensory overload. A prime example was the conferences of States parties to the Convention, which were nearly unbearable for some autistic persons.

16. His organization fully supported the inclusion in the draft general comment of references to members of the LGBT+ community with disabilities. It also welcomed the fact that the draft mentioned autistic persons in addition to persons with intellectual or psychosocial disabilities. It called upon the Committee to add references to autistic persons wherever persons with intellectual or psychosocial disabilities were mentioned.

17. **Mr. Jaime** (Sexual Rights Initiative) said that the Committee's recent record with regard to sexual rights, in particular the rights of gender and sexuality non-conforming persons with disabilities, gave cause for concern. The recognition of diversity in sexual orientation, gender identity and expression, and sexual characteristics in the initial version of the Committee's general comment No. 6 (2018), on equality and non-discrimination, had been watered down in the final version, which contained only one reference to lesbian, gay, bisexual, transgender and intersex persons with disabilities, in paragraph 33, on the consultation obligations of States parties under articles 4 (3) and 33 (3) of the Convention.

18. It had been expected that draft general comment No. 7, which elaborated on the same articles of the Convention, would contain a substantive analysis of the impact of sexuality and gender on the participation of persons with disabilities. However, all three of the references to lesbian, gay, bisexual, transgender and intersex persons with disabilities in the draft general comment were enclosed in brackets, which suggested that they were optional or subject to dispute. Although the draft included references to women with disabilities, it did not contain any substantive analysis of the impact of sexuality and gender on their participation.

19. His organization was concerned that failure to address the exclusion of lesbian, gay, bisexual, transgender and intersex persons with disabilities in the draft general comment would undermine the long-standing and progressive recognition of rights related to gender and sexuality by the other human rights treaty bodies, the special procedures of the Human Rights Council and the Council itself. Persons with disabilities and those who had suffered

discrimination on the basis of sexuality and gender expression had a shared experience of exclusion, one that involved historical, structural and intersecting discrimination. Medical and legal institutions had denied their right to bodily autonomy, which was gaining increasing recognition as a concept that underpinned the full range of sexual rights to which all individuals were entitled. The Convention was recognized as a treaty capable of addressing intersectional discrimination and sexual and reproductive rights. His organization called upon the Committee to continue to strive to protect the sexual rights of persons with disabilities in the course of its work and thereby to demonstrate that lesbian, gay, bisexual, transgender and intersex persons with disabilities were included under the slogan "Nothing About Us Without Us".

20. **Ms. Piggot** (Inclusion International) said that the comments of previous speakers had highlighted the importance of ensuring the participation of persons with disabilities and the support that they needed to defend their rights confidently and competently. The need to make processes and information accessible and relevant to the lives of persons with disabilities had also been highlighted. She would urge the Committee to ensure that the final version of the general comment recognized the full diversity of organizations of persons with disabilities and the importance of self-advocacy for such persons.

21. **Mr. Habegger** (insieme Schweiz) said that his organization was working on a project to support self-advocacy groups in Switzerland. His personal experience as the older brother of a person with Down syndrome, however, had made him aware of the importance of including families in decision-making processes.

22. **Ms. Jenni** (insieme Schweiz) said that her achievements owed a great deal to the support of her family.

23. **Mr. Hodgson** (International Commission of Jurists) said that, although draft general comment No. 7 dealt in some detail with the provision of reasonable accommodation for persons with disabilities in the context of participation in social and public life, it did not focus specifically on the participation of such persons in decision-making processes relating to the provision of reasonable accommodation. He wondered whether the Committee had taken that aspect of the topic into account. If not, he would urge it to do so. The process of providing reasonable accommodation should be centred around the needs of persons with disabilities as expressed by those persons themselves.

24. **The Chair** said that the process of providing reasonable accommodation had been dealt with at length in the Committee's general comment No. 6, in which the Committee had enumerated the seven elements that guided the implementation of the duty to provide reasonable accommodation. It might make sense to insert a reference to general comment No. 6 into draft general comment No. 7.

25. **Mr. Hodgson** (International Commission of Jurists) said that it would be useful if draft general comment No. 7 could elaborate on paragraph 26 of general comment No. 6, which concerned identifying and removing barriers that had an impact on the enjoyment of human rights for persons with disabilities, in dialogue with the person with a disability concerned.

26. **Mr. Langvad** said that most of the issues raised in the discussion had in fact already been addressed in the most recent version of draft general comment No. 7, which differed significantly from the initial version. The current version addressed the question of the extent to which organizations of children with disabilities were representative, the inclusion of persons of various sexual orientations and the specific needs of groups such as autistic persons.

27. Articles 4 (3) and 33 (3) of the Convention concerned not the provision of reasonable accommodation for individuals, but the participation of organizations of persons with disabilities in decision-making processes relating to the development of legislation and policies to implement the Convention. It would be possible to address the participation of persons with disabilities in decision-making processes relating to the provision of reasonable accommodation, but such issues were already covered in general comment No. 6.

28. In the course of the discussion, he had noted a number of points that he would delve into further, but it should be borne in mind that the Committee was constrained by the word limit applicable to general comments. In any case, he expected that the final text would prove satisfactory to the majority of stakeholders.

29. **The Chair**, welcoming the speakers' recommendations, said that the Committee attached great importance to its cooperation with organizations of persons with disabilities.

The discussion covered in the summary record ended at 4 p.m.